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**THE NHS SICKLE CELL & THALASSAEMIA PROGRAMME
PUBLIC OUTREACH:
An Evaluation Report**

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EXECUTIVE SUMMARY

The NHS Sickle Cell & Thalassaemia Programme: Public Outreach Report was commissioned to provide an overarching evaluation of the outcomes, learning and developments from three outreach projects commissioned by the NHS Sickle Cell & Thalassaemia (NHS SC&T) Screening Programme, as part of their overall communications strategy.

The aim of these projects was to raise awareness about Sickle Cell and Thalassaemia and the screening offer amongst communities that were most at risk from the conditions.

In South London a drama was produced on DVD about Sickle Cell to target primarily the African community; in Tower Hamlets a “health guides” model was used to engage the local Bengali community to raise awareness of Thalassaemia and in Manchester outreach workers were used to engage with the Pakistani and South Asian communities, again talking about Thalassaemia.

The evaluation has been conducted in two phases. The first phase was a limited evaluation to assess the initial success of the outreach projects. The second phase was a review and update of the earlier evaluation after the projects had been running for a while and after recommendations from the first evaluation had been implemented. This second phase review was carried out by Eileen Worrow, who worked during the first phase as an evaluator for Barbara Burford Consulting Ltd (BBCL).

For the purposes of evaluation, it should be noted that these projects were set up to provide education and information to the target audience. Because of the nature of screening which involves personal choice, it was never envisaged that there would be a direct call to action (ie to attend screening) as a result of the interventions. Therefore the original brief for the evaluation was deliberately limited and pragmatic. In terms of the public, it was to test whether participants understood more about the issues after the outreach sessions and found them appropriate and useful. In terms of the providers and the agencies, the aim was to look at how the projects were managed and to identify learning that could inform future work.

In the first instance, BBCL looked at evaluation forms from attendees at outreach sessions together with some paperwork from the outreach workers. Interviews were also conducted with the outreach agencies, some key stakeholders and a limited number of members of the public who had attended sessions. At the second stage, there was more information upon which to base the evaluation, as recommendations from the first stage had been taken on board and the outreach agencies had established more robust methods of monitoring and reporting progress.

This report will therefore outline the initial findings and provide an updated evaluation of progress made since then.

Summary of findings in general

- All three outreach models were successful in what they set out to do, which was to raise awareness of the conditions in the targeted communities. The projects were very well received and feedback from the public and from outreach workers and stakeholders was very positive.
- The projects demonstrated substantial information need amongst the targeted populations ie people at higher risk for Sickle Cell and Thalassaemia. They also showed that proactive outreach is an effective way to engage audiences outside the normal NHS channels. **Hence, it is recommended that the Programme continues to invest in this work and also seeks opportunities to bid for external funding and explore partnership opportunities.**
- Whilst the pilot projects have been successful, **there is a need to develop a sustainable approach that can reach beyond the current geographical areas and which is financially sustainable given the current economic climate.**
- The outreach work contributes directly to achieving core objectives for the Screening Programme – for example around supporting informed choice, developing the capacity of primary care to engage in screening and care, engaging men in screening, developing materials for the public and providing opportunities to hear the views of the public. **The outreach work therefore needs to be fully integrated into the overall communications strategy.**
- Although the outreach work was not designed to drive demand for testing, it has raised the issue of how tests can be provided where people request them. Although NICE recommends preconceptual counselling and provision of testing for populations at higher risk*, there is currently no National Screening Committee or Department of Health policy on offering screening outside the pregnancy journey and hence no established systems and mechanisms for offering a test. The evaluation recognises that this is a long term agenda which the Screening Programme is working to address both at a policy and practice level and, in particular, in its work around engaging primary care.

* 1.6.3.1 Pre-conception counselling (supportive listening, advice-giving and information) and carrier testing should be available to all women who are identified as being at higher risk of haemoglobinopathies, using the Family Origin Questionnaire from the NHS Antenatal and Newborn Screening Programme. (www.sickleandthal.org.uk/Documents/F_Origin_Questionnaire.pdf)

Source: Antenatal care: Routine care for the healthy pregnant woman
NICE, March 2008

- Of the 3 projects, the South London DVD model has the most potential for expansion by its very nature as a media product. With TV, film and internet coverage the possibilities for reaching wider audiences are endless. Visual products as educational tools are an invaluable resource; audiences are more readily engaged and therefore more responsive to further discussion of the subject afterwards. The product could be used as part of a package supplied to trained outreach workers in different areas. The programme should consider developing a similar product for Thalassaemia.
- The success of each project was achieved in large measure through the efforts of a key champion. **The Programme needs to think carefully about the**

qualities needed to drive this kind of work in order to ensure success in other areas as well as to build upon the work already achieved.

Lessons learned to inform future work

One of the key learning points from these projects is that there is a need to balance two – potentially conflicting – dynamics. On the one hand it is valuable to have educators who are themselves from the target community. These people are seen as credible, approachable and ideally they both literally and figuratively speak the local language. On the other hand, it is important that the people doing the outreach have sufficient clinical knowledge to grasp the quite complex points involved. These projects do not have a simple call to action – eg eat 5 a day, do more exercise. Rather they involve conveying quite complex ideas about genetic inheritance, risk, screening as well as sensitive cultural issues.

Both the Programme and the agencies have been aware of these issues for some time. This finding is also backed up by the mapping exercises conducted in both Tower Hamlets and Manchester. Potential partner agencies were happy to provide access to their clients but did not want to conduct the sessions themselves as they were not confident that their workers could be given sufficient training to convey the messages accurately.

In all areas, pragmatic steps were taken to achieve the balance between local credibility and clinical expertise. In Tower Hamlets, it was increasingly the trained specialist counsellor who took on the educational role. In Manchester, the project leader had been involved over the whole project and had built up an unusually strong grasp of the subject. In South London, the DVD project is being run by an experienced person from the Sickle Cell Society.

However, this need to balance local and clinical knowledge is absolutely fundamental to the future strategy for outreach.

Some preliminary discussions have already taken place exploring a model in which more experienced people are recruited as outreach workers (eg specialist nurses or counsellors or even qualified expert patients). These people would be provided with a “kit” of materials and with a more robust accredited training.

It is recommended that the Programme undertakes a review of the available evidence for approaches along these lines and also looks carefully at issues such as training, supporting the workers, recruitment and management of the projects at a local and national level.

INTRODUCTION

This evaluation report sets out, in as much detail as possible the findings of BBCL in the first phase, and Eileen Worrow in the second phase, as evaluators of the NHS Sickle Cell & Thalassaemia Screening Programme's commission of 3 outreach projects.

SECTION 1:

NATIONAL AND LOCAL POLICY CONTEXT

The NHS Sickle Cell and Thalassaemia Screening Programme is part of a group of National Screening Programmes managed by the UK National Screening Programme (NSC). Its remit is to implement the statement within the NHS Plan:

...to offer effective and appropriate screening programmes for women and children including a new linked antenatal and neonatal screening programme for haemoglobinopathy and Sickle Cell disease.

Sickle Cell and Thalassaemia are serious inherited blood conditions that can have a profound effect on affected individuals and their families. The disorders affect haemoglobin in red blood cells which, in turn, reduces the ability to carry oxygen around the body. They are the world's most common inherited disorders.

In England, Sickle Cell disorders are estimated to affect more than 1 in every 2,400 births. 240,000 people are thought to be healthy carriers and more than 12,500 people have the disorder. The highest prevalence is amongst black Caribbean, Black African and Black British populations.

Beta Thalassaemia Major is thought to affect more than 700 people in England with 214,000 healthy carriers. The highest prevalence is amongst Cypriot, Italian, Greek, Indian, Pakistani, Bangladeshi, Chinese and other South East Asian populations.

The aim of the programme is to enable informed reproductive choice and to ensure that appropriate care is planned and delivered for affected children.

The NHS Sickle Cell & Thalassaemia Screening Programme as part of the UK National Screening Committee was set up in 2001 to implement antenatal screening for Sickle Cell and Thalassaemia (SC&T) and newborn screening for Sickle Cell.

The context for outreach work

From the outset, public outreach was an integral part of the Programme's overall communications strategy. There were a number of reasons for this:

Firstly, the Programme had concerns about how the communities most at risk were likely to perceive the screening offer. In particular, there were concerns that a screening

programme which included the option of termination could be perceived in a negative light. There was a real danger of the media presenting screening as “terminating black babies” and the Programme was asked to give a ministerial briefing about these risks. These concerns were exacerbated by the fact that in many other countries offering SC+T screening (such as Cyprus, Iran, Bahrain), the public health agenda is around eradicating the diseases. In England, the key driver has always been informed choice – including an informed choice to say “no”. Hence one of the reasons for the outreach was to be seen to take steps to reassure the public about the motives for offering screening.

In addition to these risks, the Programme was also aware that there were particular communications challenges in terms of:

- Very low public awareness and knowledge of SC+T
- Widespread stigma and myths
- Low general understanding of concepts such as genetic screening, inheritance, risk
- The fact that SC+T particularly affects BAME communities with consequent risks of prejudice and stereotyping and the fact that some BAME communities may be harder to reach and less engaged in health services
- The fact that SC+T are unevenly spread across England
- The fact that this programme was asking for contact with a health professional much earlier in pregnancy than the traditional NHS timescale (by 8-10 weeks rather than the norm which was well after 12 weeks). This timing made it all the more urgent to inform people about early screening and also to communicate the message that screening can be offered at any time in life. As recommended by NICE, there are clear benefits in at risk populations knowing about SC+T before they start a family so there is time to understand the issues and choices without the pressure of a developing pregnancy.

The communications strategy was informed by three key pieces of research:

- Preliminary Community Consultation – Krista Maxwell-Atungo, which was carried out in May 2002. This involved consulting with people who were considered to be opinion formers/leaders amongst key at risk populations
- Sickle Cell and Thalassaemia qualitative research report, Populus June 2004, which focused on the views of members of the public from relevant at risk communities
- Towards a Communication Strategy for the NHS Sickle Cell & Thalassaemia Screening Programme – A Planning Framework – Futures Group Europe. This built on earlier research and made specific recommendations about the aims and content of the communications strategy.

The findings and recommendations from these three pieces of research informed the key objectives for the outreach work, which were, in summary:

- To help to ensure that the screening programme was developed and presented in a way that was acceptable to at risk communities and to develop materials and

- information in an iterative way drawing on experience of what was useful and what was not.
- To try to remove some of the barriers to engaging in screening by challenging stigma and exploding myths
 - As recommended by the Future Group, to address the central challenge of how to get women to present for antenatal screening early by raising awareness about the conditions, about screening and about why they might be at risk

At a more operational level, some of the additional objectives were to:

- Develop transferable learning about delivering public outreach
- Enable a sustained programme of public outreach and education across England building on learning from the initial projects
- Involve key stakeholders such as the voluntary sector in SC&T, providers of SC&T care, patients and relevant health promotion agencies in order to build knowledge, capacity, sustainability and credibility
- Engage the public in dialogue to find out more about their perceptions of the disorders, the screening process, cultural and societal issues and any barriers to accessing services
- Use this project to inform future communications work for the SC&T screening programme and for the NHS more widely

At a local level, the main aims were to:

- Develop interventions that were relevant to the local population and that built on existing expertise, networks and communications channels
- Work with local stakeholders and partners and explore sustainable partnership opportunities

Success Criteria

For the purposes of this evaluation, it is important to note that the Programme made a conscious decision that the success of the outreach work should not be measured in terms of increased demand for screening. The key reasons for this were:

- The decision to accept a screening test is a personal one. The goal of the Programme is to support the public to make that decision in an informed way. If a person has received appropriate information and decides to reject a screening test, that is a successful output in the sense that the information was provided.
- It was felt that offering a test immediately after an education session might make people feel pressured or might mean that they accepted a test before they had really thought through the issues
- Despite the fact that NICE recommends preconception counselling and testing for at risk populations, there is currently no established infrastructure to offer testing outside mainstream maternity services. Where the test was offered after an education session, this was generally because the outreach project had established a relationship with the local Sickle Cell and Thalassaemia

counselling service. It was recognised that primary care is the ideal setting for preconception testing but putting that in place is a long term agenda with complex policy, funding, systems and communications challenges.

- Despite the fact that demand for testing was not set up to be a key success measure for the outreach project, this issue is one of the key discussion points for the evaluation project as discussed below.

Target audiences

Initially the strategy was to focus on population groups where there is higher prevalence of SC&T. In addition, the programme wished to reach out to audiences who have traditionally been less able to access information or who have been less well served by services.

Within these communities, the primary audience was women and men who were sexually active/actively planning a child/expecting a child

Secondary audiences include: the wider family, the wider community and opinion formers within the community

In each geographical area, particular population groups and people within those groups were specified. This was based partly on perceived information needs and partly on a pragmatic assessment of the programme's ability to reach these populations and their willingness/capacity to engage with the programme.

It was decided that, since the screening programme has only a small core team, it was important to identify outreach agencies with existing links to target populations to deliver the interventions. The criteria for selecting the agencies were that:

- They were able to use a social marketing approach to ensure that there was good initial understanding of local knowledge and information needs
- They had proven methodologies and channels for reaching the target audiences
- They were able to engage local stakeholders including services, patients and the voluntary sector

Areas to Consider

There are misconceptions and stigma attached to inherited diseases in most communities, and issues are often not discussed for fear of blame being attached to the carrier or his/her family, or fear that sons or daughters will not find a suitable marriage partner if the subject of inherited disease is brought out into the open.

With SC&T, ignorance of the causes of these diseases lead people to link them with other blood related disorders such as HIV and AIDS and Hepatitis, and can lead to the assumption that they can be passed on in the same way.

Other issues to consider are religious views regarding termination, and the fact that the course of nature should not be interfered with, ie. "it is better not to know if a child is likely to be disabled or have an inherited disease, because then difficult decisions will not have to be made".

Most married women will want to discuss this with their husbands and will also often wish to seek permission from their husbands before agreeing to screening.

SECTION 2:

THE PROCESS

The NHS SC&T Screening Programme commissioned Ethnos Research and Consultancy to explore ways of supporting the delivery of public education by engaging with ethnic minority populations at a local level. It was decided at an initial meeting that the interventions should be selected based on a combination of the following:

- That they should target communities that are known to be disproportionately affected by SC&T;
- They should target communities that have the least awareness and knowledge of the conditions and that are least likely to understand and accept the message of the Screening Programme;
- That they should be developed both in areas where the target communities are well established and supported by a developed and capable BME community and voluntary sector, and also in areas where this is not the case, with a view to developing capacity in such areas;
- That they should be developed by partnerships that involve the Programme itself, and statutory, community and voluntary organisations that have expertise in either working with the target communities, or in devising and delivering health outreach programmes, or in SC&T.

ETHNOS were initially given the following broad aims to consider for the Agencies who would be selected to carry out the interventions. The aim of these interventions was to support informed choice by:

- Providing a safe space where issues can be explored in an open, non-prescriptive and culturally appropriate way
- Providing information about the disorders
- Clarifying the concept of risk (generically and for specific populations)
- Explaining the screening offering and the choices that may arise
- Talking about the services to support an affected child
- Trying to give people a picture of the impact of the disorders – emphasising that severity of the disorders may vary widely and the experience of the family will depend on a variety of factors including their own perceptions and those of the communities in which they are living
- Making people aware of some of the ethical issues that arise from screening

- Obtaining feedback from local people about their views on screening, the conditions, the kind of public outreach initiatives that are helpful, any other ideas about what is needed in the way of public information / education / services

The programme identified several geographical areas within which they wanted ETHNOS to scope potential organisations to engage in the pilots. These were chosen based on the size of the communities disproportionately affected by SC&T (Pakistanis, Bangladeshis, Black Africans, and Black Caribbeans) and the differing nature of the local communities themselves. The areas selected were:

- Tower Hamlets for the Bangladeshi population
- Southwark for the Black African (settled) population
- Blackburn and Darwen for the Pakistani population
- Bedford for the Black African (recent) population
- Barking and Dagenham for the Black African (recent) population

The research then went through 2 phases, the first of which was a scoping exercise to identify potential partners. A scoping questionnaire was developed to conduct telephone interviews with identified organisations. Of 149 potential partners identified in the 5 geographical areas, the scoping team made contact with 85. Of these, 45 organisations completed the telephone questionnaire. These were followed up by face-to-face interviews which enabled ETHNOS to recommend potential partner agencies who could best deliver the outreach projects.

The second phase involved ETHNOS working in close collaboration with these identified agencies to establish their capacity to develop the projects. Workshops were then held, with Screening Programme staff present, to obtain detailed information about the identified agencies' plans for interventions and their capacity and resource needs.

These two exercises revealed that only in Tower Hamlets and Southwark were there organisations with sufficient experience and capacity to deliver on the projects. Bradford was considered as another potential area suitable for outreach, but again, there was no overarching organisation that would be capable of delivering. It was finally decided that Manchester, with its large Pakistani community would be most suitable for the third outreach project. The same process of telephone and face-to-face interviews was carried out with potential partners in Manchester to decide on a suitable organisation to deliver the project.

As a result of the scoping exercise, the Programme commissioned three agencies to deliver the work:

- In South London, **WoMan-Being Concern** was working with the African community to develop, deliver and disseminate a drama on DVD about Sickle Cell. The dissemination of the DVD has now been taken over by the Sickle Cell Society.
- In Tower Hamlets, **Social Action for Health** is working with an established model known as "health guides" to engage with the local Bengali community – primarily talking about Thalassaemia
- In Manchester, the **Black Health Agency** is working with outreach workers to engage primarily the Pakistani community talking about Thalassaemia

SECTION 3:

THE EVALUATION FRAMEWORK

The NHS SC&T Outreach Project Evaluation – Broad Aims

The NHS Sickle Cell and Thalassaemia Screening Programme needed:

General Requirements:

- To gather information from each of the 3 agencies involved in the public outreach project to produce an overarching evaluation
- To review how the whole outreach project was managed – by both the programme team overall and by the individual agencies
- To identify key learning points across the projects in terms of processes, development of information materials, training the outreach workers, delivering the interventions
- To determine the effectiveness of the interventions by analysing evaluation data from the agencies and from the overarching evaluator's own research and interviews
- To review the potential for continuing work in these areas and for using the learning and resources developed in other areas of the country
- To determine whether the programme provided value for money for the NHS
- To obtain recommendations on whether the data obtained can be used to underpin bids for external funding

Evaluation Strategy

Essential Participants in the Evaluation Process

In using a participatory model for this evaluation it is essential that the following groups concerned are involved according to their role and responsibilities for the programme:

NHS SC&T Screening Programme Team

To explore:

- How they developed or outsourced training for those working in the outreach agencies, including any monitoring or assessment of how effective the training was

- The involvement of the team in managing the projects
- Their knowledge and support of how the agencies were taking the project forward
- Any participation in events
- Their requirements for reports and evaluations to be submitted
- Any policy and strategic decisions likely to be based on results
- Lessons learned to inform future public outreach work with at risk populations

The Outreach Agencies

To explore:

- Awareness of the need and value of the programme to the agency itself and the communities that it serves
- Effectiveness of any training received
- Any preparation work done in advance in the local community
- The involvement of various stakeholder groups in meetings held and details of any decisions made as a result
- Numbers of people who received screening as a result of the outreach work
- Feedback from those who participated in events
- Views on success of the projects and scope for expansion

Local Counsellors

To explore:

- Their level of involvement with the programme
- Their views on methods used by the outreach team
- Any feedback they may have received from local community/recipients of outreach projects

Recipients of outreach projects

To explore:

- Their level of understanding of the implications of Sickle Cell and Thalassaemia, and of the need for screening, before the interventions, and
- Their level of understanding after the interventions
- Their views on the value of the outreach projects
- Whether they received screening as a result of the interventions

Thalassaemia Society and Sickle Cell Society

To explore:

- Background
- Their knowledge of, and views on, the outreach programme

Local Clinical Stakeholders

To explore:

- Level of their involvement in the outreach programme
- Their views on delivery of the programme
- Any feedback they may have received from participants in programme

Overview / Review of Project Level Evaluation

We understood that the three outreach projects' evaluation data would be limited to basic feedback from outreach workers and those who had participated in the sessions. We initially visited each project to obtain as much information as possible on what research was done in the community in advance of the outreach, the levels of awareness of the conditions before and after the sessions and any feedback received from stakeholders. Later in the process we interviewed key stakeholders and community workers, and recipients of the outreach sessions to get their views on the success of the projects.

We also looked at how lessons learned and good practice was shared between the three projects, and whether the models used could be replicated in other communities.

The knowledge resulting from the information collected and analysed for the overarching evaluation is further designed to support the effectiveness of funding decisions; test the effectiveness of the strategies for this major funding initiative and to inform the policy debate. Alongside this, the participative model used means that while not being intrusive, the evaluators are an available source of technical assistance on evaluation at project level, if requested.

SECTION 4: THE EVALUATION RESULTS

This section will reflect feedback from the various stakeholders in the outreach projects and from the projects themselves as a result of interviews conducted by the evaluators.

NHS SC&T Screening Programme Team

- **How they developed or outsourced training for those working in the outreach agencies, including any monitoring or assessment of how effective the training was:**

The Programme worked with Cynthia Gill, a noted Haemoglobinopathy Specialist Nurse and with the local counsellors in each area where outreach was being developed. It developed its own training course delivered by Programme members and the local counsellor. This was a full day covering basic knowledge of the conditions; the key messages for outreach work; a presentation about the

Programme, the screening offer and why the outreach programme was being developed: a briefing about how the outreach would be conducted in each area; and wherever possible, a presentation from someone living with one of the conditions. A quiz testing knowledge before and after the session was administered and evaluation forms collected.

This training programme was delivered several times in each location as new outreach staff came on board and also as a refresher for some existing staff. It was also delivered to some people from partner agencies eg Pakistani Resource Centre in Manchester. The content was modified following feedback from participants. Essentially, it was simplified to ensure that outreach workers were able to grasp the key messages.

Where outreach workers required clarification or additional information in response to questions from the public the Programme provided this directly to them. Both BHA and SAFH added refresher training and BHA added some additional elements eg training in consanguineous marriage and presentation skills.

A particular learning point was that the script writers for the DVD should have attended this training.

- **The involvement of the team in managing the projects:**

There were regular meeting with the project leaders. The team were very involved, through bi-weekly meetings and teleconferences, in pushing the actions, checking understanding and making sure there was clarity. Each of the agencies had issues with changes of management and with administrative capacity. This made driving from the commissioning end difficult and time consuming.

- **Their knowledge and support of how the agencies were taking the project forward:**

The team found that many of the normal project management processes that would normally rest with the owners of the commissioned project such as admin, setting up, logistics, training and more were brought to them for general management as opposed to by exception when issues needed to be escalated.

In hindsight it was felt that they had been too optimistic in their assumptions of the level of local operational support required, the working practices and work ethics of the various agencies and that in future these must be checked and clarified. In the second phase of the outreach work, much tighter management systems were put into place by the Programme. The Programme also terminated the contract with WomanBeing Concern and engaged the Sickle Cell Society which had much better systems and processes.

- **Any participation in events:**

The team attended several BHA and SAfH events – both events with the public and events involving local partners and stakeholders. The events for WomanBeing were sessions in which local people and service users were consulted about their views

and experiences of Sickle Cell to inform the development of the script. They were not considered suitable for the Programme to attend as this could have biased the discussion.

- **Their requirements for reports and evaluations to be submitted**

The Programme asked for evaluation forms from the public attending events and reports from the outreach workers delivering the events. SAFH provided feedback forms from recipients of training and community sessions and also gave feedback on information materials. BHA provided more extensive evaluation data from participants and outreach workers. During the second phase, much more comprehensive reporting and data was received from the agencies.

- **Any policy and strategic decisions likely to be based on results:**

At a national policy level, the key area for consideration is the provision of testing for people who request it. As noted above, NICE recommends preconception counselling and carrier testing for those at higher risk (ie target audiences for outreach work)*. However there is no current National Screening Committee or Department of Health position on this as yet. The Programme is working to raise discussion about these issues at a policy level. It also has a strand of work exploring engagement of primary care which is the most likely setting for delivering pre-conception testing.

* 1.6.3.1 Pre-conception counselling (supportive listening, advice-giving and information) and carrier testing should be available to all women who are identified as being at higher risk of haemoglobinopathies, using the Family Origin Questionnaire from the NHS Antenatal and Newborn Screening Programme. (www.sickleandthal.org.uk/Documents/F_Origin_Questionnaire.pdf)

Source: Antenatal care: Routine care for the healthy pregnant woman
NICE, March 2008

- **A view of Return on Investment (ROI):**

Yes, perceived as being a good return on investment rather than being shocked at late diagnosis. They believe that early detection helps lessen public costs for management of disease, but are even more concerned with lessening the emotional costs to families and individuals. The projects help people to examine the risk factors and cultural implications associated with close marriages; fear of stigma; and lack of knowledge.

Thalassaemia Society and Sickle Cell Society

- **Their knowledge of, and views on, the outreach programme**

The Society was very closely involved only with the WomanBeing Project through:

- Taking part in the original Ethnos research and subsequent workshops to discuss the way forward

- Setting up consultation workshops and pulling out key aspects of experience from service users
- Recruiting service users
- Locating a drama group
- Workshop presentations
- Reviewing and commenting on drama script
- Helping to train dissemination volunteers
- Providing a representative for the national outreach steering group

During the second phase, the Sickle Cell Society took over the dissemination of the DVD.

United Kingdom Thalassaemia Society

The United Kingdom Thalassaemia Society (UKTS) was established more than 30 years ago. Its aims and objectives are for the relief of sickness and for the protection and preservation of public health by:

- The relief of persons suffering from Thalassaemia and related or similar disorders
- Advancing the education of the public, including medical practitioners, in all aspects of Thalassaemia and related or similar disorders in particular by promoting and coordinating research into its causes, treatment, prevention, and permanent cure, and by disseminating the useful results of such research

When UKTS was first established, its focus was primarily on the Greek and Turkish Cypriot communities, where the risk of Thalassaemia was highest. Within those communities UKTS was dealing mainly with the parents of children with Thalassaemia, as the mortality rate from the disease was quite high and children often did not reach adulthood. With advances in medicines and treatments this is no longer the case.

Since 2002 a large part of the agenda has been to work more closely with at risk Asian communities. This has been a very slow and difficult process, due to the fact that UKTS has only one office in London, which is staffed by one full time and two part time workers. In spite of this, links have been made in the Midlands and North of England, and patient conferences are now held in both these locations. Their parliamentary reception included people from Blackburn, Sheffield and Birmingham, and UKTS roadshows have visited locations across the country where there are established Asian communities. They are at present in the process of organizing a programme of seminars or health days for young people in 6th form and colleges in the target areas. Their lack of resources however means that they are very limited in what they can do geographically.

How UKTS were involved with the outreach projects:

They were involved in the original Ethnos research, and provided a representative for the steering groups and attended meetings. They also supported the Tower Hamlets

project with simplifying their leaflets. UKTS did offer a simple method of explaining genetics with the use of coloured balls, but this was never used.

Their knowledge and support of how the agencies were taking the projects forward

The screening programme has done a lot to further the cause and raise awareness. The Tower Hamlets project was most successful when Noorjahan the community nurse was there; once she had gone it did not have the same impact, as once the sessions had ended there was no signposting or follow up. The Bengali community in East London is quite recent and is therefore a fairly closed and hard to reach community. A large proportion of the people do not speak English, so much simpler messages are required. The recent cartoon booklet in Bengali which was produced by the programme centre is very childlike and simple, but it does get the message across because it is so easy to understand.

A view of return on investment and value of the outreach to the targeted communities

Any incentive to raise awareness is worthwhile but there is a danger when it is targeted to one particular area that a lot of money can be spent on training and maintaining the outreach but the returns will be limited. More work should be done via the media, ie. radio and television because for one outlay many more people can be reached. UKTS have produced 2 DVD's, one on screening and one on living with Thalassaemia, both of which are free of charge from the Society. The Sickle Cell drama is very good but they do not think that a drama would be appropriate for Thalassaemia because it would need to cover too many different cultures.

WOMANBEING PROJECT

The evaluators were shown the DVD Family Legacy, which was extremely well produced and very moving. It was deemed to be very realistic by those who had seen it. Part 2 of the DVD which we did not see at that point, includes real life interviews with people who inspired the characters in Family Legacy, a mock Sickle Cell consultation, and facts from members of the Sickle Cell team. Three consultations were carried out to obtain real life experiences to include in the DVD. Later, we were sent some evaluation feedback on the community consultations and workshops which were held in advance of producing the DVD, and also copies of the finished product.

The dissemination phase of the DVD project, which has been taken over by the Sickle Cell Society, has been very successful. Extensive media coverage has meant that the DVD has now been seen by a very wide audience, both in UK and abroad, and innovative ideas for circulation now and in the future aim to ensure that the message reaches an ever widening audience.

The Outreach Agency

- **Awareness of the need and value of the programme to the agency itself and the communities that it serves:**

Those working on the project were very aware of the need for the programme in relation to the target community.

- **Effectiveness of any training received:**

Training was provided to members of the WomanBeing team and some potential community partners. Initially, members of the community were to be used in the DVD, but it was then decided to use professional actors, so there should have been no training need there. Any training would be for those who are going to be involved disseminating the DVD product. No work had yet been done on this during the first phase. In the second phase, the dissemination work was undertaken by Iyamide Thomas who has extensive knowledge about Sickle Cell and who has worked closely with the Screening Programme. Hence no additional training was required.

At the start of the dissemination stage, it was envisaged that community organisations such as West African Networking Initiative (WANI), Carers of Life and African Advocacy Foundation (AAF) were going to deliver the dissemination with their workers being trained to get the messages across. It was found however that this was unrealistic in terms of time and complexity of training, and that it would make more sense to use people who were Sickle Cell experts and who could answer questions at the events. The project leader Iyamide Thomas has personally facilitated the screening sessions to date. She is now training up additional people who have clinical knowledge and who can reliably facilitate an informed and clinically accurate discussion session. These include four SC&T nurse specialists, and a French speaker. This will enable significant expansion of the project.

- **Any preparation work done in advance in the local community:**

Three consultations were carried out to obtain real life case studies to include in the DVD. Workshops were organised, with PowerPoint presentations and discussions about the best way to present the drama. 55 people took part in the consultations, including those living with Sickle Cell and their carers.

Meetings were held at dissemination stage with community organisations all of whom were keen to help with the project. Carers for Life have grass-root support networks in the community such as barbers and hairdressers and places of religious worship. The project visited 7 shops, all of whom wanted to help with the DVD.

- **Feedback from those who participated in initial events:**

Participants of the workshops concluded that the project is very timely, and that a DVD highlighting the issues around Sickle Cell was needed to bring more prominence to the subject. There was discussion about the stigma and discrimination that often affects people with Sickle Cell, and participants thought that education was needed to dispel myths. It was suggested that young people should be prominently involved in production of the film.

The DVD was launched in October 2008, and members of the audience were given feedback forms to complete. General comments were that the DVD was excellent, and that it should be used to raise awareness in other at risk communities. There were several comments that it should have air time on TV. Those members of the audience who worked in the health or media sectors said that they would use the DVD in their work. Several people thought that a similar product would be useful to raise awareness of Thalassaemia.

Feedback from participants of sessions during dissemination

Participants of outreach sessions were given questionnaires to fill in after the sessions. The majority were very positive about the DVD and of its value in raising awareness of Sickle Cell.

Analysis of questionnaires from outreach sessions in January 2010, which were attended by around 250 people showed:

- 82% of respondents thought that the film captured the key issues and gave useful information on caring for someone with Sickle Cell
- 78% said that they had learned something new from the session
- 58% of respondents who did not know if they were carriers said that they would like to find out after having seen the DVD and 17% were unsure.
- Of those respondents who said that they did not want to find out, the main reasons were either that they were too old, or that there was no evidence that testing would be relevant within their family
- 93% of respondents agreed that screening should be offered to both men and women before starting a family
- 74% agreed that although the DVD portrayed a British Nigerian family, other high risk groups would find it relevant to them
- 57% said that they would show the film to other people and 45% said that they would be willing to take part in follow up interviews at a later date.
- 84% of respondents described themselves as Black African, Black Caribbean or Black British
- 31% of those who responded to the gender question stated that they were male, and 52% were female
- Ages of respondents varied from 16 to 80 + with the majority being from the 30-59 age group

These results clearly show that the sessions were meeting their objectives in raising awareness.

Comments were also received from the online evaluation form which is linked to the online DVD. There have been well over 1,000 hits on the website to date. Some of the comments are shown below:

Question 3 –Having Watched the Family Legacy did you learn anything new?

I learnt that siblings of parents who are carriers or traits can be completely clear of having the disease. As I thought children of parents who are carriers or traits would either be carriers themselves or contract the disease. That is what I learnt.

That you can live with the disease without necessarily dying from it

Question 10- Please provide any other comments about the film

Not only did I find the film extremely informative I also found it emotional as I am a Sickle Cell trait and only found out when I was pregnant with my son back in 1982 through a routine blood test. My husband is also a trait and I underwent a pheotoscopy at the hospital in South London (sorry I can't remember the name of the hospital) near Camberwell Green as I lived in Peckham at the time. Thank the Lord my son is a Sickle Cell trait as well, I also had another son in 1993 he too is a trait. My eldest son is now 27 years old and after watching this film I will impress upon him the importance of ensuring that his future partner has a screening as he is a Sickle Cell trait. I read about this film in The Voice newspaper once again, the film is very informative and I hope it continues to educate the masses.

(Female, age 40 to 49, Black Caribbean in the UK)

This film was watched by my two sons aged 10 years and 7 years whom both found it very interesting, and learned a great deal that I could not have told them about the disease myself. Thank you, and I will be passing on this information to all that I can.

(Female, age 30 to 49, Black Caribbean in the UK)

I am a Sickle Cell sufferer and the film brought back many memories for me, as when I found out I was pregnant (even though I was using birth control) my partner also refused to take the blood test to find out weather or not he was a carrier as he said, we do not have such illnesses in his family. I found the film very informative.

(Female, age 40 to 49, Black British in the UK)

This was a wonderful introduction. Let's do Multiple Sclerosis next time. Thank you

(Female, age 50 to 59, Black Caribbean, country unspecified)

The film was amazing, I have a daughter who has Sickle Cell b-thalasemeia. I teach SCA at Mcgill universtiy because of my daughter. This film was so good that I would like a copy if possible . please contact me to see how I can get this film to show others .

(Female, age 50-59, European in Canada)

• Views on success of the project and scope for expansion:

The dissemination phase of the project has resulted in the DVD and accompanying information reaching a very wide audience, due to extensive media coverage and local projects. Plans for the next six months aim to extend the screenings into areas in North

and East London. There are also plans to screen the film via Alumini, (associations for ex pupils from secondary schools in Africa), Masonic associations, places of worship and various other forums.

Media coverage has included several TV and radio broadcasts, screenings at Film Festivals and articles in newspapers and magazines, as well as screenings at community events and support groups. One of the screenings on BEN TV included interviews with the project leader and two people with Sickle Cell, one of whom had been very involved in production of the DVD. His experiences were used as inspiration for one of the characters in the film.

A very notable achievement was the screening of Family Legacy on prime time TV in Sierra Leone. Iyamide gave a copy of the DVD to a friend who works at the Sierra Leone Human Rights Commission (HRCSL). A film was shown every Thursday during May as part of a "Festival of Human Rights" films on SLBC. The film was followed by 25 minutes of discussion on issues raised, and the programmes were interactive with the opportunity for viewers to text in comments and questions. Reaction to the Family Legacy was very positive, with viewers asking where they could buy the film, and discussion of several issues including informed choice, discrimination and stigmatisation of sick people. There was also discussion on government obligations to provide information and care for those with Sickle Cell within the new free medical health care schemes. The programme has since been repeated.

A BME television station that showed the DVD has expressed an interest in either making a full length film – Family Legacy 2, following the story as the child with Sickle Cell is growing up, or in making a soap along similar lines. This proposal is being investigated by the project leader and would obviously have the potential to raise awareness of Sc&T on a much wider scale.

Contacts have been made with 3 West African airlines with a view to on board screening of the DVD. Information on the DVD was also mailed to 14,000 people worldwide via the Georgia Comprehensive Sickle Cell Centre.

Locally, contacts have been made with community organisations who have grass-root support networks. As a result of this there has been a very successful screening in a local barbers shop at which 20 men participated and completed questionnaires afterwards. Several other shops have also expressed an interest in participating, and the project is looking at incentives to encourage local businesses to take part. The DVD is being disseminated through other means, such as libraries and colleges, and there are plans for raising awareness through service providers such as health professionals, school staff, social services and housing.

The project is also in the process of organising family home visits. One such visit has already been facilitated by the project leader with 14 people attending, and 15 more are planned over the next 6 months.

This outreach project is already reaching people nationwide and abroad and has the potential to go much further due to the media vehicle and the internet. The model could also be replicated in other outreach projects.

Whilst this project has been contracted to the Sickle Cell Society, in practice it has been developed and led by one person, Iyamide Thomas. The project has depended on her extensive knowledge, networks and personal commitment. Iyamide is very highly regarded within the Sickle Cell community and brings extensive understanding of the condition to the project. Her energy in networking and seeking out opportunities and very strong media contacts has been invaluable to the success of the outreach. For future development of this work, it is important to understand that personal leadership is a key factor.

BLACK HEALTH AGENCY PROJECT

At an early site visit an interim project evaluation report was made available to us, and we had a long discussion with the project leader regarding her future plans for the outreach. We were also given access to some feedback forms from outreach workers and participants of the sessions. BHA were also in the process of developing a monitoring toolkit to evaluate the process at all stages, including their engagement with other organisations, and this was forwarded to us when it was completed. A second site visit was arranged at which a BBCL evaluator was enabled to have access to various stakeholders of the project, including recipients of the outreach Sessions.

At the second phase, another visit was arranged where the evaluator made contact with staff from the partnership organisations, project workers and clinical stakeholders.

This outreach project has been strengthened in the second phase by linking up and working with other voluntary community organisations in the area and training staff from these organisations to run the awareness sessions. The Pakistani Resource Centre, The Roby Centre and Surestart are all hosts to a range of different community groups and events, and this has enabled the project to deliver to men and women of all ages and from various communities. The project is also using Asian Sound radio and local media events to publicise the outreach.

A key success factor in this project has been the sustained leadership of the project manager Shabana Baig. Shabana has invested substantial personal commitment to the project and has acquired an exceptionally good understanding of the issues for a non clinical person. She has personally forged the links with partner agencies and steered the project in line with feedback from the public, for instance the development of the presentation and the factsheets.

The Outreach Agency

- **Awareness of the need and value of the programme to the agency itself and the communities that it serves:**

The success of this project was due to the efforts and organisational skills of the project co-ordinator, rather than to Black Health Agency itself. It was clear that the project co-ordinator and her staff were very aware of the need and value of the programme to the communities BHA serves.

- **Effectiveness of any training received:**

All outreach workers have received training and agreed that it was very effective. The initial training by the SC&T Centres in London and Manchester has been followed up by attendance and observation at awareness sessions, and by regular refresher courses and revision with the project leader. The initial training materials were adapted during the course of the project in accordance with feedback from users and focus groups, and a PowerPoint presentation was developed for use with the target community.

The project leader delivered training on issues around confidentiality, and on working with BME groups (including BME workers) and on the importance of monitoring and evaluation. These issues were not included in the original training but have now been included.

Training courses are ongoing, the most recent being Consanguineous Marriage training which was delivered by Dr. Amra Darr. Some of the comments from recipients of the training course are below:

"I thoroughly valued this training. It was interesting; the issues covered were dealt with appropriately taking into account people's lack of medical knowledge. The training dealt factually with a lot of assumptions and beliefs that are widespread in specific communities. I think it should be mandatory for all frontline staff working with patients."

"The whole day broadened my knowledge; the information will be very useful in my role engaging with the very diverse community that I work in"

"the training has given me the confidence to answer the cousin marriage question when delivering sessions"

"inspiring presentation. Very informative and grounded with experience and research. The content was adapted to suit everyone at the training and it provided a forum to explore some issues that were personal and that maybe people would find difficult to engage with. The group discussions added context, content and common voice. This issue needs to be given more room to be explored."

- **Any preparation work done in advance in the local community:**

Black Health Agency have links with many organisations and community groups in Manchester, and these links were used to establish the level of awareness of SC&T amongst the target group.

Six focus groups were set up to:

- Check what people knew before the intervention.
- Develop ideas and strategies on how best to deliver information and raise awareness
- Test existing materials – e.g. NHS flyers, BHA monitoring tools
- Assess the needs that were not addressed
- Gather all related information – i.e. myths, challenges, stigma etc

Prior to delivering the outreach programme the presentation was trialled through conducting a baseline survey of existing knowledge in the community. Sessions were delivered through the focus groups and changes made to the presentation materials and delivery based on the feedback received. The project worked with established

community organisations that were in contact with BHA to identify the actual groups. Consultation was carried out with a total of 44 South Asian men and women aged 21 to 74 of whom 25% of the participants were men and 75% were women.

- **The involvement of various stakeholder groups in meetings held and details of any decisions made as a result:**

A steering committee was set up, comprised of members of voluntary sector organisations, service users and community groups. This group met monthly and various decisions were made, such as involvement of GPs during the next stage, and developing sessions for young people, and involvement of Surestart.

- **Numbers of people who received screening as a result of the outreach work**

A monitoring toolkit is now in place and computerised records are kept to collect quantitative data. To date, 174 people have been screened. There are still some problems with “Did not attend” but these have been reduced since the appointment letter has been translated into four community languages, and a method for keeping in touch with referees has been set up.

- **Feedback from those who participated in events:**

Participants at the sessions were given feedback forms to fill in, and these were generally very positive and complimentary of the workers and of the information they had given. They liked the fact that translators were available, and they liked the PowerPoint presentation, which they said was very clear. Some people had said that it would be helpful to have more case studies and examples at the sessions, and more visuals, such as videos in other languages. Some comments from service users:

- *“I think this work BHA is doing is so good for the community, I have learned a lot from the information session they did. I attended the Thalassaemia Centre with Shabana and her team to be tested. I was so pleased when I visited there because the nurses were so nice and explained everything very well and it was actually a lovely experience and I tell everyone about it. I have 4 children, with special needs and I felt it was very important to be tested in order to rule out any further problems. I have also spoken to my husband and he will be getting tested soon”.*
- *I heard about this many times but didn't understand it, finally it makes sense!!”*
- *“I didn't know how important it was, the session made me realise what it means if I am a carrier, I want to get tested now and tell all my family”.*
- *“It is very beneficial to have a session like this, which I can understand fully*

- **Views on success of the projects and scope for expansion**

The project workers all thought that the initiative had been very successful and they felt that they had made a real contribution to the community. They said that results of questionnaires given to participants had shown that awareness of the conditions had increased by up to 80% and that people were much more comfortable about

discussing the subject. Those who had Sickle Cell or Thalassaemia or who had children or relatives with the condition had now found a forum to talk to other people and to ask advice.

Partnership working with Surestart, the Pakistani Resource Centre and the Roby Centre have meant that sessions can be delivered to a much wider range of people in environments which are familiar to them. Workers from the Pakistani Resource Centre and the Roby Centre have been trained to deliver outreach sessions, and regular sessions are held at Surestart group events.

The project workers stated that they receive numerous calls every day asking for sessions to be held within community projects and at events, and at one stage in February they had to put people on hold because the diary was completely full for 5 weeks ahead. They have received enquiries from Oldham and from other parts of Manchester. Distribution of flyers and posters resulted in contact from an outreach worker from Pakistan who was in Manchester and has a daughter with Thalassaemia. He subsequently delivered a session in Urdu on caring for a person with Thalassaemia and conveying how his daughter has taken on major challenges in order to overcome the debilitating effects of the condition.

Information sessions have been delivered on Asian Sound Radio, one in Urdu and another in English for a younger audience. These sessions were promoted for two weeks prior to the programme via 30 second advertising slots. Asian Sound said that they received many calls after the programme and are interested in repeating it.

An information stall was set up at the Asian Lifestyle Wedding & Fashion Exhibition to promote awareness of Sc&T and 166 people were engaged over two days, the greater proportion of whom were in the 18-35 age range.

All of the workers at the project, and from those partner organisations who work with them are of the opinion that the outreach is now really gaining momentum and should be carried on and expanded to cover other areas.

Black Health Agency are now in the process of developing a Best Practice Manual for outreach initiatives, taking on board some of the lessons learned from this project.

Recipients of Outreach Project

- **Their level of understanding of the implications of Sickle Cell and Thalassaemia, and of the need for screening before the interventions**

Those interviewed said that before the interventions, they had no knowledge at all of the implications or need for screening. Some had heard of Sickle Cell and Thalassaemia, but did not know anything about the conditions, and did not know that their community was at high risk.

- **Their level of understanding after the interventions**

The levels of understanding increased by up to 80%. This figure was reached by evaluation of pre and post session questionnaires, and of feedback from session

workers and participants. We were told that people now discuss the subject at community gatherings, and older people are spreading the word to their families and neighbours. Young people interviewed have told their friends and teachers. One young couple had requested screening entirely on what they had been told by someone who had attended a session.

Analysis of feedback forms for the 6 month period Oct 09 to March 2010 showed that 98% of respondents felt they had gained knowledge about Sc&T disorders.

- **Their views on the value of the outreach project**

All of those interviewed were very positive and enthusiastic about the project. Some of the comments recorded were:

- *very valuable and worthwhile, should be given to other at risk communities;*
- *very important that the community knows how this could affect them;*
- *when I heard about the symptoms, it made me realise that my relative who has a sick baby in Pakistan is probably affected. I will make sure my family are screened.*
- *So much useful information, and I was very surprised that so many people in my community could be affected*
- *I had been told that I had the trait, but had no idea what that meant until I attended one of these sessions. I am now receiving help and advice.*

Local Counsellors

An interview was held with one local counsellor during the first phase of the project.

- **Level of involvement in outreach programme**

Was a member of the steering group, and gave advice and recommendations. Ran awareness sessions with the project, gave a speech and provided case studies on Thalassaemia.

- **Their views on delivery of the programme**

It has definitely made a big difference as far as awareness of the diseases and screening options available, because it has made other people in the community and extended family aware, rather than just pregnant women. The results so far have been excellent.

But I think a lot of resources have been wasted. For instance, a session was held for older women, where transport was paid for, and special facilities laid on, when in my opinion we should be concentrating on educating the younger people, and letting them raise awareness with their older relatives.

Also, a lot of money is spent on translation, when the majority of people who need the screening already speak English. It is only older people and new arrivals who need translation, so it would be more cost efficient to do it on a needs basis.

Note from evaluators: This particular project did not spend any money on translations, as they employed bi-lingual session workers.

In my opinion, more work should be done with young people in Universities and schools, and I also think that if there is another phase to the project, then we should be educating school teachers, university professors, GP's, carers and hospital workers, to enable them to educate others.

There is not nearly enough said about Thalassaemia as a disease. Those who are presenting the awareness sessions seem to lump Sickle Cell and Thalassaemia together, as if they are the same disease, when in fact they are very different, with different treatments and very different patient needs.

- **Any feedback they may have received from participants in programmes:**
This person worked specifically with people with Thalassaemia and did not really have any contact with those who had participated in the programme.

Local Clinical Stakeholders

Interviews were held with three people from the Manchester Sickle Cell and Thalassaemia centre.

- **Their level of involvement in the outreach programme**

The Centre has been involved from the start of the project and has regular meetings with the project leader. They helped initially with providing training materials and putting together presentations, and this support is ongoing. Staff from the centre attend outreach sessions to give expert advice and answer questions.

- **Their views on delivery of the programme:**

Staff from the Centre agreed that the programme was very worthwhile, and was now reaching a much wider audience due to partnerships with other organisations. They said that information gained from the outreach helps them to deliver their services better, for instance the appointment letters are now translated into four languages, due to feedback received from the project.

When asked if they thought that the sessions would be better delivered by Sc&T experts, they all agreed that there was room for both experts and community workers to work together. They felt that most people respond much more positively to a familiar environment with project workers from their own community who can speak their language; community workers should be used to convey a basic understanding of the subject and then refer people to the experts for further advice.

The evaluator mentioned that several people had expressed an opinion that testing should be made available at the same time as the awareness sessions. The response to this was that it is not as simple as just providing a test. Consideration has to be given to:

- The counselling element – there would have to be somewhere available where confidential counselling could take place
- Clinical risk assessment – hygiene considerations, health and safety, safe disposal of sharps etc.
- Time element - blood samples have to be tested on the same day they are taken

Overall, the Centre believes that the outreach programme has made a real difference to awareness of the conditions in local communities and has resulted in a definite increase in referrals. They think that it should be rolled out to cover the whole of the North West area as there are no Sc&T centres in Oldham, Bradford or Leeds.

We also spoke to someone who has Sickle Cell and who has worked for the Sickle Cell Society. He is now chairman of the support group and a patient representative for the Screening Programme. He has delivered presentations and training sessions for the outreach project and given advice on the content.

He feels that the outreach has brought a level of awareness to the community that was previously lacking. Now that links have been established and the foundations have been built, there needs to be a rolling programme for engaging communities. In his opinion, the money saved by the NHS in bed days and treatment as a result of raising awareness, far outweighs the cost of the outreach projects.

- **Any feedback they may have received from participants in programmes:**

Participants who are referred to the centre are generally very positive and enthusiastic about the outreach.

THE SOCIAL ACTION FOR HEALTH PROJECT

An initial meeting with the project leader and a health guide provided information on what the agency was doing to raise awareness in the community. The Health Guide model had been developed by SaFH and was now being adopted by the local PCT. The model had been adapted for this project to hold more one-off sessions, as it was found that younger people preferred this approach, whereas older people were more comfortable with several sessions to enable them to really understand the subject. Although some data had been collected on evaluation forms, it had not been collated and the project leader promised to send it to us once it had been completed.

At a later stage, a second site visit was arranged at which a BBCL evaluator was enabled to have access to various stakeholders of the project, and from this we were able to measure to some extent how successful the project had been.

The Outreach Agency

- **Awareness of the need and value of the programme to the agency itself and the communities that it serves:**

This is a well established agency, with years of experience in outreach work, and a stated awareness of the need and value of the programme.

- **Effectiveness of any training received:**

A training day for Health Guides was delivered by the National Screening Programme to give them a basic understanding of the conditions and the types of screening available. After the initial training by the National Screening Programme, work was done to develop a more simplified message to be used in the outreach sessions. When we spoke to the project workers, the established health workers who had worked on other projects with SAfH were more positive about the training, but still thought that more training would have been useful. Some of the voluntary workers did not feel that they had enough training before giving awareness sessions. They thought that some training on presentation skills would have been useful, and more explanation of the conditions by health professionals. One project worker interviewed was decidedly confused about whether or not Sickle Cell was an inherited disease!

Later on in the project, a bilingual specialist nurse/counsellor was recruited who was based at the Tower Hamlets Sc&T Community Service. She delivered training sessions to 11 ACE workers. The feedback from this training was excellent, and the trainees said that they felt much more confident in delivering the outreach sessions as a result.

The involvement of the nurse/counsellor was a key success factor in this project as she was able both to improve the training to other outreach workers and also to deliver sessions having an in-depth clinical understanding of the issues. In addition, she was from the local community and was able to deliver the sessions in Bengali. This is a key learning point from this project and suggests that it is highly worthwhile to seek out people who can bring specialist skills to the outreach work.

- **Any preparation work done in advance in the local community:**

Thirteen local organisations, community and voluntary groups were contacted to assess levels of awareness in the community and the need for outreach sessions within their organisations. There was initial reluctance by some organisations to participate, because of lack of knowledge about the conditions, and the fact that they were concentrating on what they thought were more important messages on diabetes, heart disease and asthma. Repeated visits and contact resulted in sessions being organised in most of these organisations.

- **The involvement of various stakeholder groups in meetings held and details of any decisions made as a result:**

An advisory group for the project was set up which included a Consultant Haematologist from Barts, a bilingual nurse from the Tower Hamlets Sickle Cell and Thalassaemia Community Service, carers and users from Tower Hamlets SC & T Society and Tower Hamlets PCT. The group met quarterly. Some members of the group helped the project significantly by contributing towards the development of the appropriate resource materials such as fact sheets and by supporting and helping the project activities.

- **Numbers of people who received screening as a result of the outreach work:**

There was no facility for referrals or screening to be offered during the first phase of the project. A specialist nurse/counsellor worked in collaboration with the project during the second phase, providing one to one counselling and being the main contact for self-referrals and blood testing, but there is no data to hand to assess whether these referrals were as a direct result of the outreach work.

- **Feedback from those who participated in events:**

The Health Guides reported that it was very hard to make people understand the implications of the conditions; even those who spoke English found the clinical terms and explanations very hard to understand. Some women were fearful that having a screening test could result in miscarriage, and others considered that this type of thing was "*in the hands of God*", so they would rather not think about it. Any leaflets used needed to be in Bengali, and much more simplified, with pictures and diagrams

- **Views on success of the project and scope for expansion:**

With help and support from the Programme centre a mapping study was set up to identify existing services engaging with the target population and to explore opportunities within these to engage with the work on Thalassaemia in Tower Hamlets. Questionnaires were sent out to GP's, statutory and community services and other health care and health promotion professionals, and this was followed up by visits and one to one interviews. 17 organisations in total took part, and it was clear from the findings that most of these have only a limited knowledge of Sc&T, and only a very small number offer any services in relation to the conditions. The greater majority however indicated a willingness to engage with the project to help with the outreach.

A seminar was held in November 09 to launch the mapping study results and to explore how to develop a widely accessible community based screening programme within primary care services. Local clinicians, health professionals and local frontline community groups were invited to attend.

Around 50 people attended this session and took part in discussions about the future for this kind of work. In line with the results from the mapping study, it is clear that local stakeholder partners are happy to provide access to their client groups but prefer sessions to be delivered by SAFH (ie by trained workers).

Bilingual ACE workers were used to run community based outreach sessions. There were 22 sessions in all, and 298 participants. Three of these sessions were male only and 2 mixed gender. The purpose of these sessions was:

- a) To enable local people to make an informed choice both about participating in screening and deciding on action as a result
- b) To encourage them to get support in relation to their decision

The sessions were very well received and there were requests for additional outreach to be delivered. The evaluation forms that accompanied the sessions were

mainly observations by those delivering the sessions so did not give any in depth data on whether awareness had been raised to any extent. The questionnaires seemed mainly to concentrate on whether participants were interested in screening; however, a good proportion did express an interest in screening, which would indicate that the sessions were meeting their objectives.

A Thalassaemia support group was set up to meet bi-monthly and was facilitated by the specialist nurse/counsellor. Once she left the project, the group folded.

Media coverage included a live talk session on Channel S, the Bengali TV channel, in May 2008 and again in November 2009. This channel has half a million regular viewers in the UK, and the show created a huge response from the Bengali community. There have also been features on local radio and in the press. Information stalls were placed at community festivals and events and a total of 327 people visited these. Several people suggested that there should be a mobile screening unit made available.

The project has been successful to an extent in raising awareness in the target communities, but there is still much to be done. Language and cultural barriers are predominant in this particular community and these need to be addressed if the project is to be sustained. Partnership working with community organisations could help to alleviate some of these problems, as could more simplified information in community languages.

Recipients of Outreach Sessions

- **Their level of understanding of the implications of Sickle Cell and Thalassaemia, and of the need for screening, before the interventions:**

There appeared to be little or no understanding in the local community.

- **Their level of understanding after the intervention:**

The response to this was varied. Some women interviewed said that they were a little better informed, but found it very difficult to understand after just one session. Others said that they had learned a lot, and were much better informed. The reasons for the different responses could possibly be due to levels of literacy in English and spoken-language barriers, but also to insufficient training of project workers. As in other projects, younger people were much more responsive and able to understand the implications and the need for screening.

- **Their views on the value of the outreach projects:**

All those interviewed said that they thought the project was very worthwhile, and that it was very important to educate the community about the risks of Sickle Cell and Thalassaemia. Several people mentioned that if awareness were raised to the level whereby the numbers of people with the conditions could be reduced, then in the long run the NHS would be saving money on treatments.

- **Whether they received screening as a result of the interventions:**

None of those interviewed had received screening, but several said that they would when a system for referrals had been set up.

Local Clinical Stakeholders

- **Level of their involvement in the outreach programme:**

Dr Paul Telfer, consultant haematologist at Barts was very involved from the outset. He was a member of the steering group and gave consistent support throughout the project.

Noorjahan, a specialist bi-lingual nurse/counsellor, provided one to one counselling to individuals and carers 3 days per week. She was the main contact for self-referrals and blood testing.

SECTION 5: THE EVALUATION OUTCOMES

The key findings and recommendations from phase one have been included here to give a complete picture of the evaluation results from the start of the projects. The majority of these were however subsequently taken on board, and are taken into account in the overarching recommendations from phase two.

Key Findings from phase one.

- The training developed by the projects, particularly Black Health Agency, for local disseminators was rated as effective.
- Community project workers and health guides are an invaluable resource, both in terms of local knowledge and in being able to impart messages to the community; but they themselves need to be assured of both a platform and environment in which to use their skills as well as continuing access to professional advice and support and stability in their roles.
- All 3 projects reported at the outset that there was an extremely low level of awareness and understanding of any aspect of the conditions within the target populations
- Since the interventions, the Tower Hamlets (SAfH) and Manchester (BHA) projects report that there seems to be a much higher level of awareness, and some of the myths and stigma surrounding the conditions appear to have been dispelled – Levels of awareness in South London could not be assessed at this first stage, as dissemination had not yet begun.
- There is very little or no information being given to at-risk patients by some local GP surgeries, although this does vary from area to area. Many people would welcome more discussion with their own GP on the subject.

- The target communities prefer information in visual formats, such as picture books, DVDs, picture leaflets, with basic, easy to understand text in simple English or in their own language..
- Linking with, and holding awareness sessions within established community groups produces good results; engenders open discussion in a familiar environment where people feel more confident in airing their views. It also helps when trying to impart complex and sensitive messages if they are presented by trusted peers who can speak community languages.
- Young people and single men and women in all of the target populations have expressed a desire for screening, so that they know whether they are carriers before entering into relationships.
- Outreach sessions with older people can be invaluable because they will engender discussion within their own families as well as with other elders who tend to be respected and have great influence in the community.
- Innovative interventions in the community benefit greatly from careful listening and consulting, and the setting up stages can be much longer than usually experienced in other types of projects.

Key Recommendations from phase one:

- The commissioners of these projects must ensure that they grasp the benefits that have emerged and build a programme that takes them forward as the building blocks of any future work..
- Strategic analysis should be used to refocus the programme and its purpose and a scoping study carried out to examine the best way forward to integrate it into mainstream health provision **Evaluator's comment:** the programme have started to look at working with GP's and primary care, and a strategy for engagement is presently being developed. This has however to be developed within National Screening Programme policy.
- It is quite urgent that the gap between expressing an interest in being screened, and having the screening carried out is tackled in all areas, but this will need focused presentation of sound evidence of demand. **See evaluator's comment above.**
- The commissioners of projects and programmes must insist on clarity of management and processes used for research projects and they must ensure that deliverables are clearly specified, and insist on delivery to time and specification. They need to become more skilled at estimating the resources needed to accomplish their proposed programme. **Evaluator's comments:** This has since been addressed by the employment of a Finance Administrator to help with budgeting the contracts and monitoring spending and by a more robust system for commissioning involving both a Business Manager and specialist commissioning expertise within King's College London.

Key Findings from phase two:

- The projects have generally been very well received. The lessons learned by the outreach can be used to inform further work on engaging with men and primary care.
- The projects show that it is important to strike a balance between having people who can credibly present the message (ie from the local community, able to speak the language) and people who have (or can be given) robust training so that the Programme can be confident that they are delivering complex messages with clinical accuracy. The Programme needs to find a way to deliver both of these objectives.
- With feedback and suggestions from the recipients and providers of outreach, training and presentations can be adapted and tailored to suit the audience. Black Health Agency did this quite successfully, continually refining the approach until they felt it was right.
- Information and leaflets are now in much more accessible formats, following feedback from outreach workers and the local community. The projects have worked closely with the Programme to achieve this. The Programme has successfully learned from this process to develop other publications and approaches for the public.
- One key person with the right skills can make all the difference to the success of projects. This has been apparent in all three projects.
- The media is an extremely powerful tool when attempting to get messages out to the wider public. The DVD project has illustrated this very strongly.
- Partnership working with other local community and voluntary organisations offers valuable ways to extend the reach of the projects to new communities.
- Men in the at-risk communities are much harder to reach because:
 - b) there is a stigma attached to what some may regard as “tainted blood” and a fear of blame being attached
 - c) men in the at risk communities do not generally regard ante-natal screening as an issue for them
 - d) men in general do not tend to access healthcare or health advice as frequently as women
- Raising awareness of the conditions within the health sector as well as in communities is vitally important, as lack of knowledge by some health professionals can lead to misdiagnosis and inappropriate treatment.
- Although the outreach work was not designed to drive demand for testing, it has raised the issue of how tests can be provided where people request them. Although NICE recommends preconceptual counselling and provision of testing for populations at higher risk*, there is currently no National Screening Committee or Department of Health policy on offering screening outside the pregnancy journey and hence no established systems and mechanisms for offering a test. The evaluation recognises that this is a long term agenda which the Screening Programme is working to address both at a policy and practice level and, in particular, in its work around engaging primary care.

* 1.6.3.1 Pre-conception counselling (supportive listening, advice-giving and information) and carrier testing should be available to all women who are identified as being at higher risk of haemoglobinopathies, using the Family Origin Questionnaire from the NHS Antenatal and Newborn Screening Programme. (www.sickleandthal.org.uk/Documents/F_Origin_Questionnaire.pdf)

Source: Antenatal care: Routine care for the healthy pregnant woman
NICE, March 2008

Key recommendations from phase two:

1. The projects demonstrated a substantial information need amongst the targeted populations ie people at higher risk for Sickle Cell and Thalassaemia. They also showed that proactive outreach is an effective way to engage audiences outside the normal NHS channels.

Recommendation: It is recommended that the Programme continues to invest in this work and also seeks opportunities to bid for external funding and explore partnership opportunities.

2. **Recommendation: Whilst the pilot projects have been successful, there is a need to develop a sustainable approach that can reach beyond the current geographical areas and which is financially sustainable given the current economic climate.**
3. One of the key learning points from these projects is that there is a need to balance two – potentially conflicting – dynamics. On the one hand it is valuable to have educators who are themselves from the target community. These people are seen as credible, approachable and ideally they both literally and figuratively speak the local language. On the other hand, it is important that the people doing the outreach have sufficient clinical knowledge to grasp the quite complex points involved. These projects do not have a simple call to action – eg eat 5 a day, do more exercise. Rather they involve conveying quite complex ideas about genetic inheritance, risk, screening as well as sensitive cultural issues.

Both the Programme and the agencies have been aware of these issues for some time. This finding is also backed up by the mapping exercises conducted in both Tower Hamlets and Manchester. Potential partner agencies were happy to provide access to their clients but did not want to conduct the sessions themselves as they were not confident that their workers could be given sufficient training to convey the messages accurately.

In all areas, pragmatic steps were taken to achieve the balance between local credibility and clinical expertise. In Tower Hamlets, it was increasingly the trained specialist counsellor who took on the educational role. In Manchester, the project leader had been involved over the whole project and had built up an unusually strong grasp of the subject. In South London, the DVD project is being run by an experienced person from the Sickle Cell Society.

Some preliminary discussions have already taken place exploring a model in which more experienced people are recruited as outreach workers (eg specialist nurses or counsellors or even qualified expert patients). These people would be provided with a “kit” of materials and with a more robust accredited training.

This model would represent a natural development of the work to date but would need careful consideration of issues such as:

- Reviewing the learning from other organisations that have used similar models of outreach and building relationships
- How the pool of qualified people should be recruited
- Developing a robust training that is accredited by the Programme
- Ensuring there is ongoing management and supervision of the outreach workers and evaluation of the sessions they deliver
- The relationship between local agencies and the outreach workers and the management of the whole outreach project

Recommendation: The need to balance local and clinical knowledge is absolutely fundamental to the future strategy for outreach. It is recommended that the Programme undertakes a review of the available evidence for approaches along the above lines

4. The outreach work contributes directly to achieving core objectives for the Screening Programme – for example around supporting informed choice, developing the capacity of primary care to engage in screening and care, engaging men in screening, developing materials for the public and providing opportunities to hear the views of the public.

Recommendation: The outreach work needs to be fully integrated into the overall communications strategy.

5. Of the 3 projects, the South London DVD model has the most potential for expansion by its very nature as a media product. With TV, film and internet coverage the possibilities for reaching wider audiences are endless, as demonstrated by the recent showing of Family Legacy in Sierra Leone. Visual products as educational tools are an invaluable resource; audiences are more readily engaged and therefore more responsive to further discussion of the subject afterwards. The product could be used as part of a package supplied to trained outreach workers in different areas.

Recommendation: The programme should explore further opportunities for raising awareness to wider audiences via media products and also consider developing a similar product for Thalassaemia.

6. The success of each project was achieved in large measure through the efforts of a key champion.

Recommendation: The Programme needs to think carefully about the qualities needed to drive this kind of work in order to ensure success in other areas as well as to build upon the work already achieved.

7. Users commented that often GP's, ambulance, accident and emergency and other hospital staff were unaware of the symptoms or treatment of the conditions.

Recommendation: The programme should look at ways of communicating with health professionals at all levels to raise awareness of the risks, symptoms and treatment of those with Sc&T.

8. Several people expressed the view that outreach should be expanded to include sixth forms and colleges of further education, so that young people are informed before they enter into serious relationships.

Recommendation: It is recommended that the Programme should consider this as a further area of work.

9. “The Family Legacy” would be an excellent resource for use in outreach sessions in Manchester if a move is made to target communities at risk for Sickle Cell and the Consanguineous Marriage training would be useful to those delivering sessions to the Asian community in South London.

Recommendation: The successful elements of the different projects should be shared

APPENDIX – CONTACTS

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Barbara Burford has been an NHS Medical Research Scientist; Director of IM&T; Head of Equalities for the NHS Workforce at the DH; and Director of Diversity for DWP. She created Positively Diverse in 1995. Other successful initiatives include; The Healthcare Apprenticeship Scheme, The Jobshop, Diversity With Purpose, Race to Improve and The Diversity Toolkit.

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Eileen Worrow has had experience of working with disadvantaged groups for many years. She joined the Civil Service in 1997 and has worked in the Employment Service, Jobcentre Plus, and DWP in the field of equality and diversity. Eileen joined Barbara Burford Consulting in 2006 and co-authored the DoH practical guides on Disability, Gender and Religion or Belief. She also took part in the evaluation of the Early Bird Mental Health training project for BME women.

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